

From ‘no problem’ to ‘a lot of difficulties’: barriers to health service utilization among migrants in Rakai, Uganda

Ruth Young¹ , Caitlin E Kennedy^{1,*}, Anita Dam¹, Neema Nakyanjo², William Ddaaki², Anne Catherine Kiyingi², Emmanuel Mukwana², Abigail Edwards¹, Fred Nalugoda², Larry W Chang³, Maria J Wawer¹, Maya Oaks¹ and Ligia Paina¹

¹Bloomberg School of Public Health, Johns Hopkins University, 615 N Wolfe St, Baltimore, MD 21205, United States

²Rakai Health Sciences Program, P.O Box 279, Kalisizo, Uganda

³School of Medicine, Johns Hopkins University, 615 N Wolfe St, Baltimore, MD 21205, United States

*Corresponding author. Bloomberg School of Public Health, Johns Hopkins University, 615 N Wolfe St, Baltimore, MD 21205, United States. E-mail: caitlinkennedy@jhu.edu

Accepted on 16 March 2023

Abstract

Migration is increasingly common in Africa, especially for employment. Migrants may face additional barriers to accessing health care, including human immunodeficiency virus (HIV) prevention and treatment, compared with long-term residents. Exploring migrants' experiences with health services can provide insights to inform the design of health programmes. In this study, we used qualitative methods to understand migrants' barriers to health service utilization in south-central Uganda. This secondary data analysis used data from in-depth semi-structured interviews with 35 migrants and 25 key informants between 2017 and 2021. Interviews were analysed thematically through team debriefings and memos. We constructed three representative migrant journeys to illustrate barriers to accessing health services, reflecting experiences of migrant personas with differing HIV status and wealth. Migrants reported experiencing a range of barriers, which largely depended on the resources they could access, their existing health needs and their ability to form connections and relationships at their destination. Migrants were less familiar with local health services, and sometimes needed more time and resources to access care. Migrants living with HIV faced additional barriers to accessing health services due to anticipated discrimination from community members or health workers and difficulties in continuing antiretroviral therapy when switching health facilities. Despite these barriers, social networks and local connections facilitated access. However, for some migrants, such as those who were poorer or living with HIV, these barriers were more pronounced. Our work highlights how local connections with community members and health workers help migrants access health services. In practice, reducing barriers to health services is likely to benefit both migrants and long-term residents.

Keywords: Immigrants, health services, HIV, health services research

Key messages

- Migrants and long-term residents faced mostly similar barriers to accessing health services, but these barriers were amplified for migrants.
- Perceived and experienced barriers depended on a migrant's existing health conditions and wealth.
- Local connections facilitated access to health services.

Introduction

Migration is increasingly common in Africa, especially for work (FAO, 2017). In Uganda, 48% of all households include a migrant and 42% of all households hosted an internal migrant (FAO, 2017). Thus, many households in Uganda are impacted by internal migration where mostly working-age members between 15 and 34 years move in and out of

the household within Uganda rather than between countries (FAO, 2017). As the number of migrants grows, understanding how mobility impacts patterns of health service utilization (i.e. how much people use health services, the kinds of services they access and when they access services) and how health systems can better meet their needs is key to ensuring universal access to services (Wickramage *et al.*, 2018). The experiences that coincide with mobility may put some migrants at risk for poorer health (Wickramage *et al.*, 2018).

Barriers to access and related poor health outcomes vary significantly by migration experience and context. Data from Africa suggest that migration is associated with underutilization of health services for chronic conditions (Ginsburg *et al.*, 2021), family planning and sexual reproductive health care (Munyewende *et al.*, 2011; Bwambale *et al.*, 2021; Sidze *et al.*, 2022), as well as with higher human immunodeficiency virus (HIV) incidence and viremia (Tomita *et al.*, 2019; Olawore *et al.*, 2018; Grabowski *et al.*, 2020). Lower health service access among migrants could be due to a range of factors including policies restricting access to local services for

cross-border migrants (Munyewende *et al.*, 2011), the cost of accessing services (Antai, 2010; Arnold *et al.*, 2014; Ivanova *et al.*, 2018; Logie *et al.*, 2021), difficulty communicating with health providers due to different languages (Arnold *et al.*, 2014; Hunter-Adams and Rother, 2017; Logie *et al.*, 2021) and distrust of local health services or providers (Logie *et al.*, 2021).

The relationship between migration and health service utilization is context-specific, dependent on both the individual migrating and the health system they are accessing (Brown and Bean, 2016; Ginsburg *et al.*, 2016; Wickramage *et al.*, 2018). In Uganda, migration is common (FAO, 2017), mostly through internal migration (Grabowski *et al.*, 2020). Uganda's health system allows migrants to use public health services for free (Walnycki *et al.*, 2019). In practice, drug stock outs, insufficient staff and limited health facilities in rural areas can cause many migrants and long-term residents to incur unexpected costs in the form of user fees at private facilities, informal payments at public facilities, transport costs or time spent searching for or waiting at health service facilities (Kiwana *et al.*, 2008; Nabyonga Orem *et al.*, 2011; Kwesiga *et al.*, 2015). Context-specific research is thus needed to understand the diversity in migrant experiences and barriers, especially for conditions that require ongoing, uninterrupted care such as HIV. Prior research largely focused on the experiences of international migrants (Lebano *et al.*, 2020), refugees (Heslehurst *et al.*, 2018; Ivanova *et al.*, 2018), undocumented migrants (Winters *et al.*, 2018) or internally displaced populations (Salami *et al.*, 2020). However, understanding barriers faced by the growing numbers of people migrating for other reasons, such as work opportunities or to live with family, is also important, especially in the context of chronic conditions like HIV where continuity of care is critical and stigma is common (Earnshaw and Chaudoir, 2009; Sileo *et al.*, 2021). Our study aims to explore the barriers to health services for migrants in south-central Uganda, focusing on the experiences of those migrating for work opportunities or family reunification reasons, from their own perspective, as well as that of health workers and local community leaders. South-central Uganda is a mainly agrarian region, with trading communities bordering the main roads and fishing communities on Lake Victoria (Chang *et al.*, 2016). In the study area, HIV prevalence is higher in study communities (range 9–43%) (Chang *et al.*, 2016) than in the rest of Uganda [5.7%; confidence interval (CI): 5.4–6.1] (UNAIDS, 2019).

Methods

Overview of data

This secondary data analysis combines data from three sets of semi-structured in-depth interviews collected in 2017, 2019, and 2021 as part of a study originally conducted to inform the design and interim evaluation of a community-based intervention that aimed to quickly link new migrants to health services, especially for HIV (see Table 1 summarizing data sources; Wawer, 2019). As part of interviews, migrants were asked about their experiences with accessing health services and with migration, while health workers were asked how migrants accessed services. We drew on these topics to better understand how migrants access health services, the reasons for migration and the challenges they face. Interviews were with migrants ($n=35$) and key informants, namely community leaders and health workers ($n=25$) (Table 1). LP, RY, and CK drafted additional questions for interviews conducted in 2021 and designed the study described in this paper, which drew from all three sets of interviews.

The study period included several relevant policy changes. First, 2017 marks the nationwide expansion of the Ugandan Government's Universal Test and Treat for HIV policy, whereby individuals diagnosed with HIV are immediately offered antiretroviral therapy (ART) (GOU, 2016). Second, since 2017 the Ugandan Government restricted fishing activity in the Lake Victoria region limiting work opportunities for migrants (Jacobson, 2019; The Economist, 2021). Third, in 2021, we conducted interviews during the global coronavirus disease 2019 (COVID-19) pandemic, and Ugandan lockdown restrictions were in place throughout the interview period, making it harder to access services (Athumani, 2021).

Data collection

Interview participants were recruited from the Rakai Community Cohort Study (RCCS), a longitudinal open cohort study in south-central Uganda. The RCCS surveys those living in the study region who are 15–49 years old. We further restricted interviewees to migrants defined as those who had migrated into communities in the study area within the past 2 years as, based on previous research, this group of migrants is more likely to acquire HIV (Olawore *et al.*, 2018). Interviewees were purposively sampled based on age, gender, HIV status and place of residence, as these characteristics reflect diverse health needs and access to health services.

Table 1. Summary of interview data sources

Data	Set 2017	Set 2019	Set 2021
Year	November 2017	February 2019	August–October 2021
Intent	To understand migration stories and experiences when accessing general health services	To test the design and implementation of a proposed intervention connecting migrants to health services, especially for HIV	Interim evaluation for the intervention connecting migrants with HIV services through CHWs
Interviewee (n)	Migrants (23) CHWs for HIV ^a (5)	Migrants (4) Community leaders (2)	Migrants (8) CHWs for migrants ^b (10) Clinic health providers (5) Supervisors of CHWs for migrants (3)

^aCHWs for HIV delivered community-based HIV care. They provided HIV counselling, testing and picked up ART.

^bCHWs for migrants linked new in-migrants to health services, especially HIV treatment and prevention, through referrals. This cadre could not test for HIV or deliver ART.

Key informants were selected based on their role in providing care to or directly interacting with migrants. Key informants included clinic workers ($n=5$), community leaders ($n=2$), supervisors of community health workers (CHWs; $n=3$) and CHWs ($n=15$). No one refused to participate. Interviewees participated in one interview each.

Interviews lasted about 55 min and were conducted in person by local, trained interviewers in Luganda or English and audio recorded with consent. In 2021, interviewers followed protocols to prevent the spread of COVID-19, including social distancing. Interviewers transcribed and translated recordings into English for analysis. Notes made after the interview described the location, surroundings and the interviewee.

Analysis

For this study, RY first reviewed data from the 2017 and 2019 interviews. RY and CK used the findings to inform the design of questions for the 2021 interviews in order to fill analytic gaps. During data collection for each set of interviews, the research team met to debrief, discuss initial findings and translations and adapt interview guides or sampling criteria based on emerging themes. Interviews with migrants reflected on their lived experiences or the experiences of others like them. Key informant interviews were used to understand community leader and health worker perspectives on migrant experiences in the community and in accessing health services. We employed thematic analysis using a constructivist perspective. RY generated the initial codes using inductive and deductive coding, drawing on existing literature and frameworks on person-centred care (Levesque *et al.*, 2013; Santana *et al.*, 2018). RY used memos and visualizations, such as draft timelines, throughout the process to help organize and understand the interview data, as well as to iteratively refine the initial codes. Based on interview transcripts, memos, visualizations and discussions with the team, some barriers were only observed at certain stages of accessing health services or among certain kinds of migrants based on their health status and wealth.

RY subsequently constructed three migrant health journeys to reflect the different migrant experiences emerging from the data. Further team discussions around migrant health journeys and the transcripts helped to identify and refine the broader themes which frame our findings. Based on our analysis, data saturation (Saunders *et al.*, 2018) was achieved for some but not all themes. This was because migrant experiences are heterogeneous and not all data were collected with these themes in mind.

Results

Among migrant participants, 21 (60%) were women and 14 (40%) were men. All migrants had either moved for work or to live with family. Women, compared with men, were more likely to report having dependents. Interviews from 2019 did not record HIV status ($n=4$); for the rest, 11 out of 31 migrants were living with HIV and 10 out of 11 HIV-positive interviewees self-reported ART use (Supplementary Table S1). One interviewee (ID28, 2017) was not on ART as she did not believe that she had HIV as she had received positive and negative HIV test results. Most migrants lived in peri-urban or fishing communities.

From the data, we created three migrant health journeys and derived four broad overarching themes around migration and health. Migrant health journeys varied based on health needs and socio-economic status. Compared with men, women were more likely to seek health services for family planning, antenatal care or child illness. Most men and women living with HIV expressed worries about accessing treatment. As noted by migrants and key informants, factors such as reasons for migration, migrants' own or dependents' health needs, job security, financial resources and whether the migration was planned all influenced access to health services. In this section, we first introduce the migrant health journeys (Part A) and then use them to reflect on the four broad themes which were generated through them (Part B).

Part A: migrant health journeys

The migrant health journeys highlight various experiences over time: (1) from arriving in a new community, (2) to deciding and researching options for health services and (3) to eventually receiving health services and drugs (Figure 1a–Figure 1). The barriers to accessing services were categorized into individual barriers, such as time and money, and interpersonal barriers, which were based on the quality and strength of relationships between the migrant and other health systems or community actors. The journeys showed the substantial variation that exists across migrant experiences: (1) 'Mary' is HIV-positive and does not have job security (Figure 1a), (2) 'Peter' is living with HIV and has job security (Figure 1b) and (3) 'Andrew' is HIV-negative and may be searching for work (Figure 1c). We describe each in greater detail below.

Mary juggles searching for work and accessing health services

Mary's journey is characterized by competing priorities for her time and resources trading off between searching for work and accessing health services. Since her arrival in the community, her experience has been stressful due to her limited social connections, wealth, access to financial support and job opportunities. Her struggle to establish herself in her new community is exacerbated by the uncertainty of her future income. She also has difficulty navigating local health systems as she has limited local knowledge. The potentially lengthy process to access ART for HIV is eventually facilitated through connections with existing local health workers or through informal ART sharing, although neither is a sustainable solution.

Andrew searches for work without needing to access health services immediately

In contrast to Mary, Andrew focuses his resources and time solely on searching for work and generating income. His lack of known pre-existing health conditions makes it easier for him to move quickly between areas regardless of access to health services. In addition, he does not need to spend time immediately accessing health services and, instead, can look for work. He, like Mary, may struggle to access health services due to his limited knowledge of local health services, wealth, access to financial resources and time. Ultimately, this will restrict how, when and where he can access services.

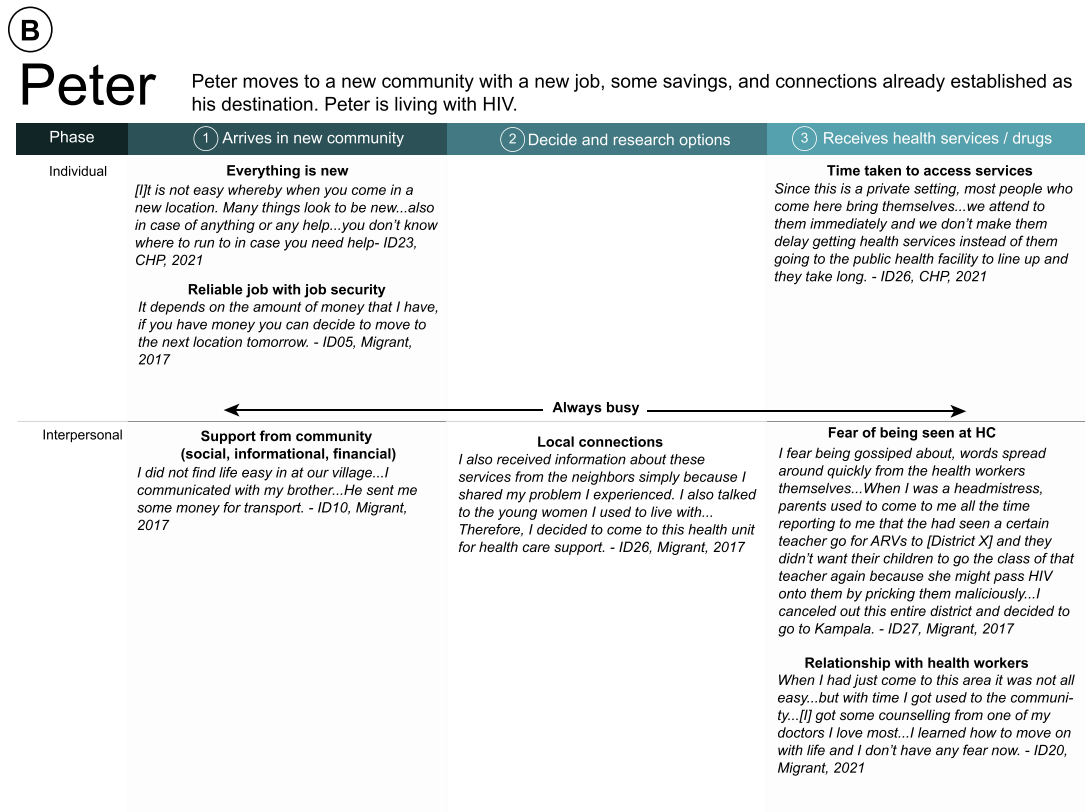
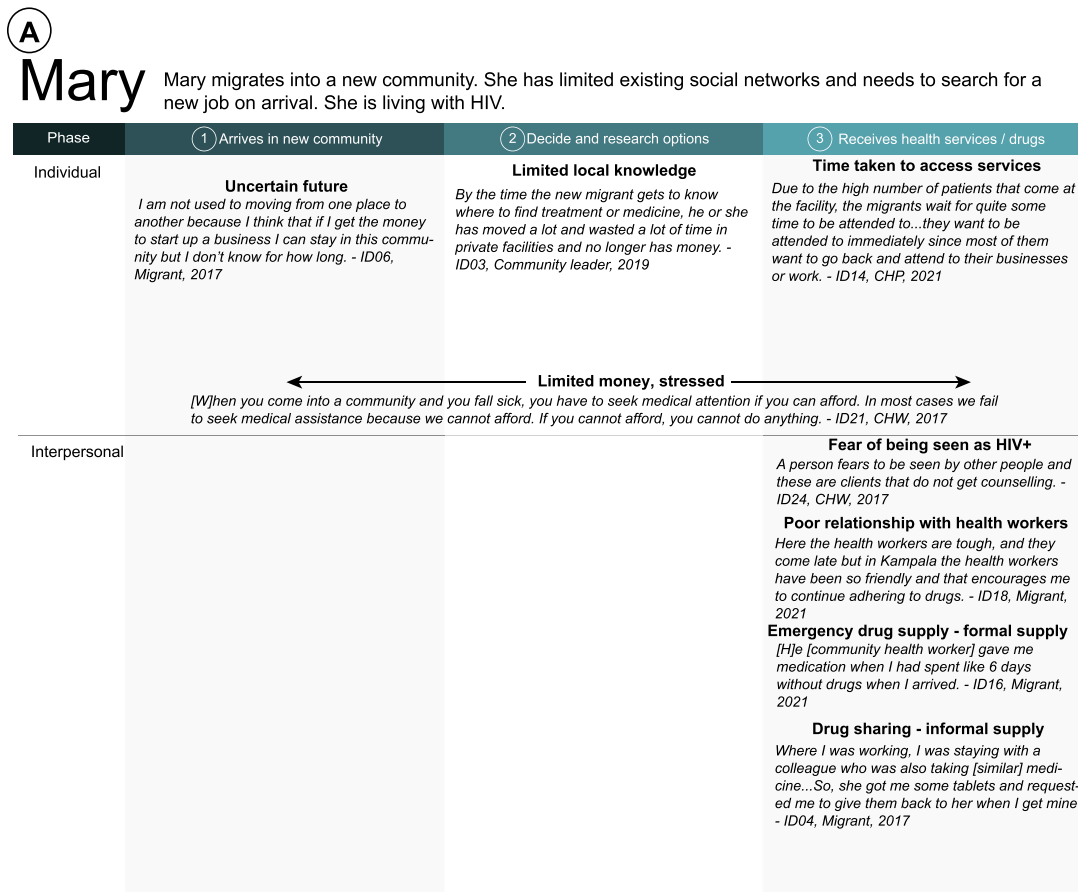


Figure 1. Representative migrant health journeys for Mary (1A), Peter (1B), and Andrew (1C)

C

Andrew Andrew moves to a new community to work. He may or may not have a job secured prior to the move. Andrew does not have any pre-existing health conditions.

Phase	1 Arrives in new community	2 Decide and research options	3 Receives health services / drugs
Internal	<p>Uncertain future</p> <p><i>I didn't feel very good about it [the move to a new community] because, I didn't know exactly what I was going to do and how it would go. - ID03, Migrant, 2017</i></p> <p>Everything is new</p> <p><i>I was so affected you know coming to a new place starting doing the work which you have not been used to, just learning everything, you find everything new to you. - ID22, Migrant, 2021</i></p>	<p>Limited local knowledge</p> <p><i>When one moves into a new community, he/she may not know where to get treatment from. - ID04, Migrant, 2019</i></p>	<p>Time taken to access services</p> <p><i>Am always busy, I can't leave my work where I get some income and go and spend time seated there [at the health center]. I see some people they may seat there...for a long time to be worked on. - ID22, Migrant, 2021</i></p>
	<p>← Always busy, limited money →</p> <p><i>I was broke and had no money, so that brought me a lot of worries but aside from that I was healthy. - ID07, Migrant, 2017</i></p>		
Interpersonal	<p>Support from community (social, informational, financial)</p> <p><i>M: [T]he move drained all my savings and I had no money by the time I had made it here. So those first days where hard.</i></p> <p><i>I: What did you do overcome those difficulties?</i></p> <p><i>M: The boss who brought me here, gave me 20,000 shillings and it helped me survive on it until I stabilised financially. - ID03, Migrant, 2017</i></p>		<p>Poor relationship with health workers</p> <p><i>[S]ome health workers are bad characters...It has helped us to know why people prefer to get healthy services from one facility compared to the others. - ID13, Supervisor, 2021</i></p>

Figure 1. (Continued)

Peter’s wealth and connections make his migration journey comparatively easier

Peter’s migration journey is characterized by his comparative job security and steady income, unlike either Andrew or Mary. Even though he is living with HIV and requires regular access to health services, his income and local connections with family, friends or work colleagues make it far easier for him to navigate the health system. He can choose where he accesses health services, bypassing barriers that Mary and Andrew face, such as difficulty getting seen by health workers. For instance, he may choose to pay for services in the private sector so that he can reduce the amount of time spent waiting for services, ensure that he can get the services he needs or travel to health facilities where he has a good relationship with health workers. His wealth also allows him to access health services further away, reducing the risk of other community members knowing his HIV status. This may protect Peter from discrimination in his new community.

Part B: cross-cutting themes

Comparing journeys of Mary, Andrew and Peter reveals how the tension between managing existing health needs and generating income can arise. Health service utilization was influenced by competing demands for migrants, health service design, the migrant experience, relationships and wealth. The four cross-cutting themes below describe the barriers and facilitators impacting health service use for migrants.

Theme 1: health services are more difficult for some migrants to navigate as they have fewer financial resources and/or are less familiar with the local health system

In general, all migrants reported having experienced stress moving to a new community. The degree of stress varied by a migrant’s wealth, defined here as job security and access to financial resources and support, with those financially struggling experiencing greater stress. Wealth was directly tied to how uncertain their future was in that community and, in turn, this uncertainty generated additional stress for migrants.

Most interviewees mentioned financial barriers to accessing health services. According to migrant interviews, financial barriers to health services were more significant to those searching for work or who mentioned money troubles, suggesting that the cost of accessing health services impacted poorer migrants. Costs derived from transport, out-of-pocket payments for health services and paying for medications. However, migrants, like Mary, frequently failed to cover all necessary costs. For example, many could not arrange transport to health facilities due to the cost of transport or limited transport options:

There are no health facilities at [Community A].... Getting means of transport to the health facility at night is worse. (ID05, Migrant, 2017)

Many migrant interviewees suggested that, in addition to money, they also spend substantial time trying to access

services and are not always successful at accessing the care they want (Figure 1a, Mary: limited money, stressed; time taken to access services). Migrants, who stated they had little time to access health services, perceived a direct trade-off between waiting for health services and earning a livelihood (see 'time taken to access services' in Figure 1a and c: Mary and Andrew).

In addition, as migrants may be less knowledgeable about local health services, they may be further disadvantaged compared with residents (Figure 1a, Mary: limited local knowledge; Figure 1c, Andrew: limited local knowledge). The chronic nature of HIV, which requires ongoing, regular access to treatment, and the tension between accessing health services and earning a livelihood exacerbate the stress experienced by migrants as they navigate new health systems. HIV-negative migrants like Andrew were unaware of potential issues accessing local health services for ongoing treatment. In contrast, migrants who are HIV-positive, like Mary and Peter, were aware of potential barriers when trying to continue their HIV treatment.

As a consequence, residents familiar with the community may spend less time and money finding health services to meet their needs. Here, a community leader articulated how medicine stock outs impacted both residents and migrants, but migrants were likely to spend more time and resources trying to navigate the system:

[T]he old residents already know how the system works.... They already know that our health facility does not have medicine. So, they go directly to private health facilities or go to far away health facilities.... However, the new migrants do not know where to find health facilities in the community unless they ask the old residents. They go to those facilities not knowing there are no medicines. They end up not getting the service and they feel bad. (ID03, Community Leader, 2019)

Theme 2: health system challenges exacerbate barriers for migrants, especially those living with HIV

Health system challenges can exacerbate the barriers that migrants with less money or time face. For example, migrants often referred to the long waiting times, frequently due to staff shortages in public sector facilities, as a disincentive to accessing health services. Additionally, while drug stock outs impact both residents and migrants, the unexpected added financial cost may have impacted migrants living with HIV like Mary more because they would have less time and money to navigate unfamiliar local health systems. If the government facility did not have medicine, they would need to search for and pay for it at another facility:

Someone may spend the entire day at the health centre but finally he is asked to go [elsewhere] and buy the medicine ... this is also a challenge for other community members but we are used to this problem. Unfortunately, this is a big challenge to the new migrant who finds no response from the health-care providers and no one hardly knows about him. (ID23, CHW, 2017)

As a result, migrants incurred costs paying for medications, spent money on transport and wasted time searching for the right medications. In contrast, wealthier migrants, like Peter,

had the means to access health services at private facilities which require out-of-pocket payments but allowed faster access to services:

Unfortunately in [this community], if you cannot travel a long distance looking for a government-aided health centre, then you need to incur high costs to access [private] health-care services. (ID12, Migrant, 2017)

One additional health system barrier was how migrants transfer their care to a facility at their destination. To transfer your care from one facility to another, patients need to have a printed transfer form or letter, which provides a basic patient history and specifies the facilities they received care from and where they are transferring care to. Many migrants do not know how long they will stay in their current community as this depends on their job and income. As a result, some migrants are unable to organize a transfer form before moving which lists the destination clinic. Once migrants have settled in their new community, they would need to return to their original clinic to get the necessary paperwork to transfer care. However, travelling back incurs additional costs and takes time. Those without transfer forms face further struggles:

I had a lot of difficulties; I came without the documents, but I was given a few drugs to continue taking as I sort out the issue of my documents. They told me to go back but when we tried to communicate with them, they told me that they had gone on leave, and they refused to give me the transfer through the phone. (ID18, Migrant, 2021)

If someone cannot transfer care or state their previous treatment regimen, health workers said they would need to 're-initiate them on ART and register them as though they were first starting out'. Reinitiating ART takes even more time for both the migrant and the health worker as migrants are retested and counselled and a clinical history is taken. This additional burden may increase the risk of someone dropping out of or delaying care. Establishing and getting health care takes time and some migrants will deprioritize health services when they also are concerned about earning a livelihood.

Theme 3: migrants living with HIV may be less likely to access health services as they fear being discriminated against because of their HIV status

Migrants living with HIV also may fear being discriminated against because of their status. This fear may discourage them from receiving care at their nearest health facility. If their HIV status was known, migrants anticipated that their local community would exclude them:

The new in-migrant might have concerns about getting stigmatized by the people in the community. [When] the long-time residents will get to know that he or she is HIV-positive, they start isolating him or her. (ID02, Migrant, 2019)

Migrants did not trust health workers to keep their HIV status confidential, and this directly led them to seek care in health centres further away. This was particularly consequential for migrants living with HIV like Peter and Mary:

Interviewer: *What prevents you from getting it from a health centre closer to you?*

Respondent: *I fear being gossiped about; words spread around quickly from the health workers themselves.* (ID27, Migrant, 2017)

Migrants like Mary, who was HIV-positive and had limited resources, could be discouraged from accessing health care as they feared being seen in a clinic and could not afford to travel to a different clinic (Figure 1c, Mary: fear of being seen as HIV-positive). Migrants may be reluctant to disclose their status to other local community members due to anticipated discrimination in their new community. In contrast, HIV-positive wealthier migrants chose where they received care, thus ensuring that their status could be kept confidential.

Theme 4: local relationships help facilitate access to health services for migrants

Migrants who had pre-existing or who developed social ties in their new communities at their destination were able to use local knowledge to help them navigate health systems efficiently. People in their new community could recommend 'good' facilities, which were those that had medicine available, were open and staffed to provide services and left patients feeling like they were heard or cared for by health providers. CHWs, family members, clinic staff and friends were all mentioned as potential sources of financial, social and instrumental support when navigating health systems. Many migrants mentioned how these sources of support had helped them access services, but few explicitly mentioned how a lack of support prevented them from accessing care.

Key informants noted that community members distrusted newcomers, especially international migrants. Part of this distrust stemmed from negative migrant stereotypes which 'othered' newcomers. Some interviewees mentioned that a few community members thought migrants were 'thieves' and 'move to our community to infect us with diseases'. Such stereotyping generated distrust between long-term residents and migrants and made it harder for migrants to integrate into their new community. A few individuals mentioned positive portrayals of migrants as 'hard workers' or entrepreneurs, but negative stereotypes were more commonly mentioned.

Migrants with social ties were more likely to successfully access health services. For those living with HIV, like Peter and Mary, social connections directly and indirectly facilitated access to ART. For poorer migrants like Mary, the advantage of having strong support networks was notable as without connections, it is unclear how she would have accessed ART. Based on migrant interviews, local connections facilitated access to health services in three ways. First, local connections helped migrants transfer care when it became too overwhelming for migrants:

I would not get the transport to [previous clinic] so ... my long-time friend who works at the health centre ... later helped access and transfer my care [documents] to the nearby health facility. (ID18, Migrant, 2021)

Second, local connections directly provided ART through health workers or friends sharing ART but this was seen as a temporary solution (Figure 1a, Mary: drug sharing and emergency drug supply). Third, several migrants sought advice

from friends or CHWs on a range of topics from recommending which facilities had their particular ART regimen, how to ensure reliable access to ART by anticipating drug stock outs or taking additional medication on long fishing trips or where to access services privately. Most migrants living with HIV also attributed their health to the efforts of providers. Trusting their health worker, having their questions answered, feeling heard or getting services in a timely manner or feeling cared for all contributed to positive relationships with health workers. Friendly staff was one of the reasons why they continued to choose a particular health centre, followed advice or were encouraged to adhere to medication as they felt someone cared. Ongoing positive relationships with health workers may make it more likely that a migrant will go to them for advice but also prevented them from moving to a facility closer to them.

Strong local connections can also help communities, and the migrants who live there adapt in times of crises. Specifically, during the COVID-19 lockdowns, curfews prevented movements between communities so individuals, especially migrants, who received ART from clinics outside their community found it difficult to access ART. Curfews also restricted the activities of CHWs who were not able to freely move into communities to assist migrants and residents alike. In addition, some residents and migrants were afraid to visit clinics for fear of becoming infected with COVID-19. Some health workers went beyond their standard duties as they delivered ART locally:

When we were in the total lockdown, there have been people who had no capacity to go to the health facility to get their antiretroviral drugs (ARVs), but these people [CHWs] take the responsibility to collect the ARVs for their clients [migrants]. (ID20, Migrant, 2021)

Without the additional support provided by motivated health workers, it is likely that their migrant clients would have been unable to access treatment. Relationships with locals or health workers helped migrants access care even if they were poor.

Discussion

Migrants experience a range of barriers to health services, which largely depend on the financial resources and social supports that migrants have access to, time available, their existing health needs and their ability to form connections and relationships at their destination. Our study corroborates findings from other African studies which suggest that migrants face additional barriers to health services resulting in under-utilization of health services (Munyewende *et al.*, 2011; Bwambale *et al.*, 2021; Ginsburg *et al.*, 2021; Sidze *et al.*, 2022). Similar to other studies, our work suggests that migrants face greater time and cost constraints associated with accessing health services (Arnold *et al.*, 2014; Kayukwa *et al.*, 2019). Reducing transport costs, providing more community-based care or addressing staffing shortages, especially in the public sector, could help improve migrant access to health services.

Migrants living with HIV face specific barriers when accessing ART. Migrants feared discrimination from the community or health workers if their positive status was known. In addition, the process to transfer ART between facilities can be onerous and prevent migrants from accessing ART.

Reducing the administrative workload needed to transfer care between facilities would help migrants accessing care at multiple facilities. For instance, making transfer processes transparent could help migrants and staff to assist in transferring patient care and enabling mobile messaging or phone calls to document transfers without relying on paper documents. Despite these barriers, networks and social connections at their destination helped migrants access the needed health services. Potentially, CHWs or community leaders could help connect new migrants to health services through outreach or through peer-to-peer interventions that can build social connections and help link migrants to community resources.

In addition, our research suggests that migrants moving for family reasons or for work reasons and over smaller distances face similar barriers to health services as refugees, international migrants and those who are internally displaced, despite Uganda being more open to refugee populations (Wickramage *et al.*, 2018; UNHCR, 2019; Walnycki *et al.*, 2019; Logie *et al.*, 2021; Rustad *et al.*, 2021). In other contexts, international migrants, refugees and internally displaced populations may face additional and larger barriers than internal migrants. However, in Uganda, under the Refugee Act of 2006, social services like the national health system can be accessed by refugees (UNHCR, 2019; Walnycki *et al.*, 2019). Even in contexts where policies guarantee access to basic services, barriers to quality services that do not impose a financial burden on marginalized populations, such as migrants, remain stubborn. As migration is so common in Africa (FAO, 2017), a large portion of the population are potentially underutilizing health services. Changes to health services to make them more inclusive of migrant populations, such as expanding clinic opening hours so they extend beyond work hours, are likely to impact a large proportion of the population and will improve access for residents too.

Furthermore, our work highlighted the importance of migrant relationships with local community members or CHWs as a way of directly facilitating access to care. Similar to other studies conducted in Uganda, connections with local community members facilitated informal sharing of ART (Rosen *et al.*, 2020) and access to health services (Amurwon *et al.*, 2017). Moreover, CHWs were key to helping people access ART during the COVID-19 lockdowns. In our study, health services were able to adapt to changing circumstances because motivated CHWs changed how care could be delivered, delivering ART directly to those that needed it. Similar studies conducted in West Africa during Ebola emphasize the importance of CHWs as an integral part of an adaptive, resilient health system (Shoman *et al.*, 2017; Miller *et al.*, 2018). To further inform this issue, a randomized trial on the impact of CHWs on HIV service uptake by migrants is being conducted in this setting (Wawer, 2019).

Migrants living with HIV face unique stressors as they need ongoing access to ART. Existing quantitative studies suggest that migrants are more likely to be viraemic than residents (Billieux *et al.*, 2017; Grabowski *et al.*, 2021), and our study alludes to potential ways to reduce barriers to accessing ART (reduce out-of-pocket payments, deliver services in the community, strengthen ties between communities and local health workers, etc.) which would benefit both locals and migrants.

Differentiated service delivery models for ART are gradually being implemented in Uganda and are likely to improve access to ART (Zakumumpa *et al.*, 2021). Differentiated

service delivery models allow individuals to access ART at facilities or within communities and through support groups or common distribution points (Zakumumpa *et al.*, 2021). During COVID-19 restrictions, the only way to access ART was through local CHWs if you were not registered at the local health facility. It was only through local, motivated CHWs that many were able to stay on ART even though movement between communities was restricted.

The transfer form process was another barrier that prevented migrants from moving ART care to their new local facility. A study in Zambia estimated that 17% of individuals traced made 'silent transfers' in the system, i.e. started ART in a new facility without proper documentation (Geng *et al.*, 2016). The transfer form system aims to transfer medical information between facilities. To help transfer information, electronic medical records or support for migrants could replace the transfer form system, but both require significant ongoing political will, large-scale reforms (e.g. identification systems and reliable power) and resources which may not be feasible.

Other countries with high numbers of internal migrants could invest in migrant-friendly health services. Based on our work, investment in CHWs and supplementing community support could help link migrants to local health services. Second, reducing administrative barriers to transferring HIV care between facilities and care, more generally, could help migrants living with chronic conditions continue to receive care after they move. Third, investing and scaling up differentiated service models where care is delivered locally would benefit both residents and migrants.

Our study had several limitations. Interviews were conducted in Luganda or English, potentially excluding international or non-Luganda-speaking migrants whose experiences may be different. In addition, during key informant interviews, we did not explicitly define what a migrant is and so insights from those interviews may reflect what they perceive to be migrants. While key informants provided important context and triangulation, their perspectives are unique and do not speak directly to the migrant experience with health services. Additionally, we coded and analysed in English, so some meaning may have been lost in translation. However, members of the team fluent in Luganda checked and contributed to the analysis process. Furthermore, our study excluded migrants who frequently moved and were restricted to south-central Uganda, and so our findings may not reflect the experiences of highly mobile migrants or those outside this region. Interviews were not solely conducted to understand migrant barriers to health services, which limited the extent to which certain themes could be explored. As a result, data saturation, whereby no new information emerges, was not reached for all codes due to the diversity of experiences and nuances with some themes. For instance, experiences with stigma at health facilities or in communities could have been explored further as it was unclear who discriminated against them, where they experienced stigma and how stigma was enacted. Furthermore, as our migrant health journeys are illustrative, they do not wholly reflect the variety of migrant experiences. In addition, interviewee reflections were shaped by the broader social context in which they took place. Notably, 2017 and 2021 coincided with tighter restrictions on fishing activity, negatively impacting livelihoods and potentially reducing migration into and increasing migration out of fishing communities

(Jacobson, 2019; The Economist, 2021), and during 2021, responses were given in the context of the global COVID-19 pandemic (Athumani, 2021). As a result, those interviewed during these periods may: (1) disproportionately emphasize the barriers to receiving health care as they were more pronounced at this time; (2) be stressed and distracted by other priorities such as their job or their health resulting in less rich interviews; and (3) some may have been less forthcoming as interviewers and interviewees could not build rapport as they would normally due to social distancing and masking.

There were several voices and topics that could be further explored in future studies. First, as we did not consider the experiences of migrants who do not speak Luganda or English, their experiences and connections (e.g. diaspora networks) may be different. Second, fear of being seen at health centres or having a reputation as HIV-positive was mentioned more often in interviews with 'privileged' migrants holding positions of respect in the community (teachers, health-related workers, etc.). Future qualitative interviews with teachers or other respected occupations could explore if perceptions or expectations of respect exacerbated the anticipated stigma associated with HIV. Additional studies could use observations and facility-level data to determine how service quality, costs, time to access services and health workers vary between facilities. In turn, this may indicate which facilities are more migrant-friendly compared with others. It would also be helpful to measure how much time (e.g. through time-motion analyses) and money is spent accessing services from the individual's perspective and if that differs by migration status or how connected they feel with communities. Finally, longitudinal interviews or retrospective migrant journey mapping could highlight how migrant experiences change over time.

Conclusion

This study demonstrates how migrants may experience similar barriers to residents when accessing health services, but, for some migrants, these barriers are much more pronounced. By understanding how different migrants experience health systems, health system actors can better understand how to deliver care to migrant populations and other marginalized communities. Our work suggests that limited time, money and local knowledge prevent migrants from optimally accessing health services. In addition, migrants living with HIV may experience these barriers more acutely. Both local connections and better information flow between facilities and communities can help reduce barriers to health services. Relationships with health providers and within the community are key in facilitating access to health services and for ensuring that services are responsive to changing circumstances. In practice, reducing barriers to services, like out-of-pocket payments, reducing stigma experienced at health facilities or making services available closer to communities, is likely to benefit both migrants and residents.

Supplementary data

Supplementary data are available at *Health Policy and Planning* online.

Data availability

A de-identified version of the data can be provided to interested parties subject to completion of the Rakai Health Sciences Program data request form and signing of a Data Transfer Agreement. Inquiries should be directed to datarequests@rhsp.org.

Funding

R.Y. was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the National Institutes of Health [award number 1F31HD1-02287]. This study was supported by the National Institute of Mental Health, the National Institutes of Health [R01MH115799] and the Johns Hopkins University Center for AIDS Research [P30AI094189]. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Author contributions

R.Y., C.E.K., L.W.C., A.D., F.N., M.J.W., N.N., W.D. and M.O. assisted with the conception or design of the work. A.D., W.D., E.M. and A.C.K. assisted with the data collection. R.Y., C.E.K., L.P., N.N., W.D. and A.E. assisted with the data analysis and interpretation. R.Y. assisted with the drafting of the article. R.Y., C.E.K., L.P., L.W.C., A.D., F.N., M.J.W. and A.E. assisted with the critical revision of the article. R.Y., C.E.K., L.P., L.W.C., F.N., A.D., N.N., M.O., W.D., A.E., M.J.W. and E.M. assisted with the final approval of the version to be submitted—all named authors should approve the paper prior to submission.

Reflexivity statement

The authorship team consisted of (1) four experienced qualitative researchers with the Rakai Health Sciences Program Qualitative Team, fluent in Luganda (local language) and English; (2) four graduate students in social sciences; (3) the director of research at the Rakai Health Sciences Program and (4) four academics at a research university in the USA. One team member, R.Y., analysed the compiled interview data as part of her doctoral research. She analysed the data from a constructivist perspective acknowledging that both the data and her own migrant background shaped her analysis.

Ethical approval. Interviewees were each reimbursed 10 000 UGX (~3 USD) for their time and transport. Each set of interviews obtained ethics approval from the Western Institutional Review Board, Uganda Virus Research Institute Research and Ethics Committee and the Uganda National Council for Science and Technology. Ethical approval for this secondary analysis of de-identified data was not required by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Conflict of interest statement. None declared.

References

- Amurwon J, Hajdu F, Yiga DB *et al.* 2017. "Helping my neighbour is like giving a loan..."—the role of social relations in chronic illness in rural Uganda. *BMC Health Services Research* 17: 1–12.
- Antai D. 2010. Migration and child immunization in Nigeria: individual- and community-level contexts. *BMC Public Health* 10: 1–12.
- Arnold C, Theede J, Gagnon A. 2014. A qualitative exploration of access to urban migrant healthcare in Nairobi, Kenya. *Social Science & Medicine* 110: 1–9.
- Athumani H. 2021. *Uganda Lifts Some COVID-19 Restrictions*. VOA, 31 July. https://www.voanews.com/a/covid-19-pandemic_uganda-lifts-some-covid-19-restrictions/6208989.html, accessed 13 December 2021.
- Billioux VG, Chang LW, Reynolds SJ *et al.* 2017. Human immunodeficiency virus care cascade among sub-populations in Rakai, Uganda: an observational study. *Journal of the International AIDS Society* 20: 21590.
- Brown SK, Bean FD. 2016. Conceptualizing migration: from internal/international to kinds of membership. In: White MJ (ed). *International Handbook of Migration and Population Distribution*. International Handbooks of Population. Dordrecht: Springer Netherlands, 91–106.
- Bwambale MF, Bukuluki P, Moyer CA *et al.* 2021. Utilisation of sexual and reproductive health services among street children and young adults in Kampala, Uganda: does migration matter? *BMC Health Services Research* 21: 169.
- Chang LW, Grabowski MK, Ssekubugu R *et al.* 2016. Heterogeneity of the HIV epidemic in agrarian, trading, and fishing communities in Rakai, Uganda: an observational epidemiological study. *The Lancet HIV* 3: e388–96.
- Earnshaw VA, Chaudoir SR. 2009. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS and Behavior* 13: 1160–77.
- The Economist. 2021. *The Reinvention of Africa's Biggest Lake*. 15 May. <http://www.economist.com/middle-east-and-africa/2021/05/15/the-reinvention-of-africas-biggest-lake>, accessed 15 March 2022.
- FAO. 2017. *Evidence on Internal and International Migration Patterns in Selected African Countries*. <http://www.fao.org/3/a-i7468e.pdf>, accessed 29 January 2023.
- Geng EH, Odeny TA, Lyamuya R *et al.* 2016. Retention in care and patient-reported reasons for undocumented transfer or stopping care among HIV-infected patients on antiretroviral therapy in Eastern Africa: application of a sampling-based approach. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America* 62: 935–44.
- Ginsburg C, Bocquier P, Bégué D *et al.* 2016. Healthy or unhealthy migrants? Identifying internal migration effects on mortality in Africa using health and demographic surveillance systems of the INDEPTH network. *Social Science & Medicine* 164: 59–73.
- Ginsburg C, Collinson MA, Gómez-Olivé FX *et al.* 2021. Internal migration and health in South Africa: determinants of healthcare utilisation in a young adult cohort. *BMC Public Health* 21: 1–15.
- GOU. 2016. *Consolidated Guidelines for Prevention and Treatment of HIV in Uganda 2016*. Kampala, Uganda: Government of Uganda. <http://library.health.go.ug/sites/default/files/resources/Consolidated%20Guidelines%20for%20Prevention%20and%20Treatment%20of%20HIV%20in%20Uganda%202016.pdf>, accessed 15 March 2022.
- Grabowski MK, Lessler J, Bazaale J *et al.* 2020. Migration, hotspots, and dispersal of HIV infection in Rakai, Uganda. *Nature Communications* 11: 976.
- Grabowski MK, Patel EU, Nakigozi G *et al.* 2021. Prevalence and predictors of persistent human immunodeficiency virus viremia and viral rebound after universal test and treat: a population-based study. *The Journal of Infectious Diseases* 223: 1150–60.
- Heslehurst N, Brown H, Pemu A *et al.* 2018. Perinatal health outcomes and care among asylum seekers and refugees: a systematic review of systematic reviews. *BMC Medicine* 16: 89.
- Hunter-Adams J, Rother H-A. 2017. A qualitative study of language barriers between South African health care providers and cross-border migrants. *BMC Health Services Research* 17: 97.
- Ivanova O, Rai M, Kemigisha E. 2018. A systematic review of sexual and reproductive health knowledge, experiences and access to services among refugee, migrant and displaced girls and young women in Africa. *International Journal of Environmental Research and Public Health* 15: E1583.
- Jacobson A. 2019. *Fishermen Fight to Survive on the World's Second Largest Lake*. National Geographic, 3 May. <https://www.nationalgeographic.com/environment/article/uganda-military-cracks-down-illegal-fishing-lake-victoria>, accessed 16 March 2022.
- Kayukwa A, Butts SA, Barylski NA *et al.* 2019. HIV prevention among Zambian itinerant workers: challenges and solutions. *Journal of Health Care for the Poor and Underserved* 30: 358–77.
- Kiwanuka SN, Ekirapa EK, Peterson S *et al.* 2008. Access to and utilisation of health services for the poor in Uganda: a systematic review of available evidence. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 102: 1067–74.
- Kwesiga B, Ataguba JE, Abewe C *et al.* 2015. Who pays for and who benefits from health care services in Uganda? *BMC Health Services Research* 15: 1–9.
- Lebano A, Hamed S, Bradby H *et al.* 2020. Migrants' and refugees' health status and healthcare in Europe: a scoping literature review. *BMC Public Health* 20: 1039.
- Levesque J-F, Harris MF, Russell G. 2013. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health* 12: 1–9.
- Logie CH, Okumu M, Kibuuka Musoke D *et al.* 2021. The role of context in shaping HIV testing and prevention engagement among urban refugee and displaced adolescents and youth in Kampala, Uganda: findings from a qualitative study. *Tropical Medicine & International Health* 26: 572–81.
- Miller NP, Milsom P, Johnson G *et al.* 2018. Community health workers during the Ebola outbreak in Guinea, Liberia, and Sierra Leone. *Journal of Global Health* 8: 020601.
- Munyewende P, Rispel LC, Harris B *et al.* 2011. Exploring perceptions of HIV risk and health service access among Zimbabwean migrant women in Johannesburg: a gap in health policy in South Africa? *Journal of Public Health Policy* 32: S152–61.
- Nabyonga Orem J, Mugisha F, Kirunga C *et al.* 2011. Abolition of user fees: the Uganda paradox. *Health Policy and Planning* 26: ii41–51.
- Olawore O, Tobian AAR, Kagaayi J *et al.* 2018. Migration and risk of HIV acquisition in Rakai, Uganda: a population-based cohort study. *The Lancet HIV* 5: e181–9.
- Rosen JG, Nakyanjo N, Isabirye D *et al.* 2020. Antiretroviral treatment sharing among highly mobile Ugandan fisherfolk living with HIV: a qualitative study. *AIDS Care* 32: 912–5.
- Rustad SA, Binningsbø HM, Gjerløw H *et al.* 2021. Maternal health care among refugees and host communities in Northern Uganda: access, quality, and discrimination. *Frontiers in Global Women's Health* 2: 626002.
- Salami B, Iwuagwu S, Amodu O *et al.* 2020. The health of internally displaced children in sub-Saharan Africa: a scoping review. *BMJ Global Health* 5: e002584.
- Santana MJ, Manalili K, Jolley RJ *et al.* 2018. How to practice person-centred care: a conceptual framework. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy* 21: 429–40.
- Saunders B, Sim J, Kingstone T *et al.* 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity* 52: 1893–907.
- Shoman H, Karafillakis E, Rawaf S. 2017. The link between the West African Ebola outbreak and health systems in Guinea, Liberia

- and Sierra Leone: a systematic review. *Globalization and Health* 13: 1–22.
- Sidze EM, Wekesah FM, Kisia L *et al.* 2022. Inequalities in access and utilization of maternal, newborn and child health services in sub-Saharan Africa: a special focus on urban settings. *Maternal and Child Health Journal* 26: 250–79.
- Sileo KM, Wanyenze RK, Mukasa B *et al.* 2021. The intersection of inequitable gender norm endorsement and HIV stigma: implications for HIV care engagement for men in Ugandan fishing communities. *AIDS and Behavior* 25: 1–12.
- Tomita A, Vandormael A, Bärnighausen T *et al.* 2019. Sociobehavioral and community predictors of unsuppressed HIV viral load: multi-level results from a hyperendemic rural South African population. *AIDS* 33: 559–69.
- UNAIDS. 2019. *AIDSinfo, UNAIDS Estimates: Uganda*. <https://aidsinfo.unaids.org/>, accessed 29 January 2023.
- UNHCR. 2019. *Uganda Country Refugee Response Plan*. <https://reporting.unhcr.org/sites/default/files/Uganda%20Country%20RRP%202019-20%20%28January%202019%29.pdf>, accessed 29 January 2023.
- Walnycki A, Earle L, Monteith W. 2019. *Towards More Inclusive Urban Health Systems for Refugee Wellbeing*. <https://pubs.iied.org/10881iied>, accessed 29 January 2023.
- Wawer M. 2019. *The Welcome Incoming Neighbor (WIN) Community Trial (WIN)*. ClinicalTrials.gov. <https://beta.clinicaltrials.gov/study/NCT03915899?patient=WIN%20&locStr=&distance=0>, accessed 12 May 2022.
- Wickramage K, Vearey J, Zwi AB *et al.* 2018. Migration and health: a global public health research priority. *BMC Public Health* 18: 1–9.
- Winters M, Rechel B, de Jong L *et al.* 2018. A systematic review on the use of healthcare services by undocumented migrants in Europe. *BMC Health Services Research* 18: 1–10.
- Zakumumpa H, Makobu K, Ntawiha W *et al.* 2021. A mixed-methods evaluation of the uptake of novel differentiated ART delivery models in a national sample of health facilities in Uganda. *PLoS One* 16: e0254214.